



CRS Parent Connection

Alabama Department of Rehabilitation Services

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Ordinary joy

by Brenda Allair

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Like any self-respecting mom of a child with special needs, I know all about Holland. I've read the poem, and I know there are supposed to be tulips and windmills. I can't often find them, but I know I'm supposed to discover them somewhere among the syringes, IEP notices and medical binders that litter my child's room. I know those tulips and Rembrandts are supposed to remind me that, even if my trip to Italy isn't going to happen, there is still joy to be found ... but where?

When my daughter, Jillian, was born in 2001 – defying the doctor's predictions that she wouldn't survive outside the womb – joy filled that small hospital room. Any tears we had were overshadowed by the amazing fact of her being alive, crying and kicking and feeding as newborn babies do.

Within weeks, though, Jillian had a long list of frightening diagnoses, and we were faced with the reality of her life-long disabilities. I simply couldn't imagine how I would ever know true joy again. Doctor's offices, hospital rooms, and the PICU certainly didn't seem like places where joy could live. Therapies that involved tears – hers and mine – didn't seem like the path to happiness, though I knew they were good for her. Even her much-awaited kidney transplant, while reason for celebration, was still fraught with more fear than



Jillian Ailliar is blind and has complex health care needs as a result of an undiagnosed syndrome

joy, knowing it was only one of the many medical challenges she faced. It seemed this never-ending journey of living with disabilities and complex health conditions couldn't possibly hold anything other than fear and worry.

I craved joy and happiness the way I craved sleep. (And we all know the intensity with which we crave sleep when our children's needs know no boundaries.) Slowly, I realized that I couldn't sit around and wait for joy to tap me on the shoulder and announce itself. I had to actively seek it out, look for it, and know that our lives should not be lived without it. More importantly, I began to understand that joy was critical to our

experience of parenting Jillian. I wanted her to live a life filled with as much laughter, hope and love as she could find, and I wanted to show my older children that our lives hadn't dimmed with Jillian's birth.

For me, joy has been found in the ordinary moments, in the everyday errands and trips to the mall that are part of living a life with three children. Sitting at Starbucks, I watch as Jillian drinks her favorite vanilla milk while my teenage children chatter about frappacinos and lattes. Driving home after a challenging outing that resulted in an exhausting tantrum, I crank up the radio in the car while we all belt out the lyrics to a silly Broadway show tune, and I grin like a fool when I hear Jillian, along with her brother and sister, singing "Popular" from the *Wicked* soundtrack in harmony. Sitting around a campfire on a quiet evening, surrounded by friends and family, I sigh in contentment as Jillian cuddles in warm blankets and eats gooey marshmallows and melted chocolate. Listening in to the sound of her brother's voice, I hear the way he describes each scene for her, giving her the words when she can't have the pictures, as he reads to her from his beloved *Harry Potter* books. Peeking in her room while on the phone with the medical supply company, I smile as her sister patiently shows Jillian how to put on strawberry lip gloss while getting ready for ballet class.

It isn't only that these are experiences that, in darker moments, I wondered if she'd ever be able to have. It's the wonder in discovering that

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State Office CRS is pleased to have Kimberly Lewis assume the role of care coordination specialist. Mrs. Lewis will have statewide responsibility for providing technical assistance to CRS social workers and district supervisors in regard to the care coordination program. She will also conduct quality assurance assessments and participate in orientation and training for CRS social workers and other staff. Mrs. Lewis has been working with CRS families for many years and will be available to interact and share with you in assuring that the family-centered perspective is an important part of our care coordination program.

*Melinda Davis
Director of Children's Rehabilitation Service*

Meet CRS's new care coordination specialist

Hi! My name is Kimberly Lewis, and I am the new care coordination specialist for Children's Rehabilitation Service (CRS), effective July 1.

People who truly know me will agree that my career path of social work was pretty much an obvious one. Having a meaningful job that would allow me to positively impact others was most important to me. So, when I declared my major, social work was my first and only choice. After just a handful of classes, it was apparent that I had found my calling.



Lewis

In 1997, I took my first social work job with the Alabama Department of Public Health's office in Grove Hill. There, I worked in multiple programs, including Maternity, Home Health, Family Planning, Medically At-Risk, and the Elderly and Disabled Medicaid Waiver programs. The small, rural setting really prepared me to work with families from a strengths perspective because resources were so scarce. A little creativity didn't hurt, either! I enjoyed working in the clinic setting, making home visits, and getting to know the locals.

After three years with Public Health, I had heard of a job opening at Montgomery's CRS office. Having shared several cases with CRS, I was already well-versed in the vast services they provided. Being a Montgomery native, moving back to my hometown would put me nearer to my family and friends. I also needed the family support, because at that time, I was a single mother raising two kids under the age of 5.

I was hired as a social worker with CRS in 2000. Although I missed my patients and the relationships that I had in Grove Hill, I instantly knew that going to CRS was the best decision I could have made.

During orientation, I was told that it takes a new worker at least a year to truly understand everything you are doing at CRS. Being the overachiever that I am, I quickly set out to dispel that myth. Boy, oh boy, was I wrong! CRS has so many layers, and working here incorporates comprehension of medical conditions, care coordination, resource linkage, and how all of those components fit together. It takes continuous learning to be a great CRS social worker. Thankfully, I was blessed to have a multidisciplinary team of social workers, nurses, a nutritionist, therapists, a parent consultant, and administrative staff who were passionate about their work to assist me during orientation. Every day was an opportunity to learn something new, and to say that I learned a lot is an understatement. The work was a challenge, but it was rewarding, and so worth it.

Shortly after moving back to Montgomery, I helped care for my grandmother who had esophageal cancer. In caring for her, I acquired numerous skills that I never thought I could or

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You make it look easy!

by Matissa Moorer, parent

Raising a child or children is no easy task in itself. Raising a child with special needs makes that challenge even greater. Even more difficult, what if you have to do all this as a single parent?

This is the life many families live each and every day. I know, because my life is one of them. My daughter Kerstin, 12, was diagnosed with cerebral palsy when she was six months old. Having a diagnosis is one thing, but not knowing what it involves is something else entirely. I had no idea what CP meant, what it would do to my daughter, or how to care for someone with it. So, the research began!

Along with the consistent research came a journey of many things unexpected. One, I had to come to terms with the true reality ... I could forget about continuing to read *What to Expect: The First Year*. This book was no longer relevant to our lives. My daughter would not reach the milestones at the outlined time frame, but, do any kids? I had to now find books that educated me on caring for a child with spastic quad cerebral palsy.

I quickly found out that Kerstin would not only have a pediatrician and dentist, she would also have a neurologist; an orthopedic specialist; ophthalmologist; speech, occupational, and physical therapists; an orthotist; a social worker; and a care coordinator; the list goes on. These doctors and specialists would talk to me about spasms, frontal lobe, cerebellum cysts, hip dysplasia, heel cord, scoliosis, seizures, feeding, weight, g-tube, and so much more.

Most of these conversations we had years before Kerstin would enter school, and we also



Matissa Moorer with her daughter, Kerstin

started discussing IEPs, FAPE, LEA, assistive technology, and so on. There are so many things that most parents don't have to think twice about. Yet, if you are raising a child with "special needs," you know these topics well. Raising our children compels us to learn about so much. For me personally, I knew that if I wanted to fully understand my daughter and how to best care for her, I needed to be active, vocal, and later, become an advocate!

Along this journey, there have been many friends and family members to encourage us. They've said things like, "When I see you with your daughter, it takes me to a place in my heart as the most precious moments I've witnessed." Said about Kerstin, "She is eternally burned into my soul. That smile, and the way I feel when I am around her; it brings tears to my eyes, I'm so full of love for her." Those words have always meant a lot to me, and they will never be forgotten.

Parenting a child with special needs may

seem easy, especially when the parent(s) have care down to a science, but it gets hard at times for all of us. We get tired. We need encouragement, support, education, and most definitely, occasional breaks! We only make it look easy because they are our angels. They need us just like we need them!

To my daughter Kerstin: You (also) make it look easy. You endured three surgeries in one year (2013), and the last surgery kept you in the hospital for most of November. Yet, you still managed to smile and persevere! Through the spasms, the seizures – You smile!

Our children, with their beautiful smiles and hearts of purity, always make it look easy!

Parents, be encouraged by this! Don't feel like you have to be super every second of every day. Take breaks. Accept help when offered, and ask for help when needed! I promise I'll take my own advice as well.

You make it look easy because there is no other way!

To read more, visit Matissa's blog, ***Growing up with Kerstin: Raising a child with "special needs"*** at www.cpaware.blogspot.com.

For additional resources on cerebral palsy, also see:

"Children with Cerebral Palsy: A Parent's Guide," edited by Elaine Germalis

"Children with Cerebral Palsy," by Archie Hinchcliffe

"Teaching Motor Skills to Children with Cerebral Palsy and Similar Movement Disorders," by Martin Sieflinde

www.epilepsyfoundation.org

www.kidshealth.org

JOY

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her accomplishments, while always cause for excitement, are not the only focus in our lives. It's the amazing truth that life is lived in precious moments and that even the smallest of those holds the capacity for true happiness. Those moments aren't about Jillian's special needs or chronic illness. These moments, these ordinary joys, are the ones I store carefully and neatly in

my memory because they are so simple, so much part of the life I almost didn't dare to dream we could have.

It would be easy to see only the darkness on this path – the worry, pain, anxiety and fear that are our constant companions. But seeing the joy in ordinary moments helps me to step out of the shadows and remember that joy, laughter, kindness and compassion can also be found along the way.

*Brenda Allair is the mother of three wonderful children, including Jillian (13), who is blind and has complex health care needs as a result of an undiagnosed syndrome. Brenda works as a teacher of students with visual impairments. She is an advocate of patient- and family-centered medical care and works with several organizations as a parent advisor. You can follow her experiences on her blog, [*Musings at Midnight*](#).*

Cool stuff!

Handy, inexpensive gadgets to help beat the heat for children with special needs

by Sharon Henderson, parent consultant

As we head into the dog days of summer, severe heat in the South can be quite a challenge for our kids with special health care needs. Here's a few recommendations to keep your child cool while you're out and about:

1. First and foremost, don't forget the sunblock or shade. But what if there's little to no shade? A **Chairbrella**, available at Academy Sports and Outdoors, may do the trick. The umbrella clamps attach and hold the handle of an umbrella on to virtually any chair (including wheelchairs) to give your child some protection from direct sunlight. The clamps can be purchased for around \$5.



A Chairbrella securely holds an umbrella on virtually any outdoor chair

You also need to use a spare umbrella for it to work, but in my experience, they really do the trick and come highly recommended. Other wheelchair umbrellas are available at Amazon for \$20 and up.



A wheelchair cup holder keeps any drink within arm's reach

2. Hydration is key. Always remember to provide your child with plenty of water or bolus fluids. Attaching a **wheelchair cup holder** – available from Amazon starting at \$7 – to a wheelchair will always have your child's drink within arm's reach. A bit more money can get you the more advanced **Mother's 3rd Arm**, which fully articulates to bring a beverage even closer. Available at Amazon, \$35.



Mother's 3rd Arm is an articulating arm to move a drink even closer to the mouth for easy hydration

3. **Frogg Togg** towels and headbands have a patented "chilly pad" that stays considerably cooler than the outside air when wet and can keep your child cool for hours. To use the built-in moisture strip, simply wet the material and place it on your child's head or around shoulders. Available at Academy, Amazon, and Walmart. Headbands start at \$5, and towels are \$12 and up.



Frogg Togg towels and headbands have a built-in moisture strip that stays cool when damp

Look for these cool tools to help you and your child enjoy the great outdoors despite the extreme heat.

Do you have any additional tips or useful items to share? If so, post them on our Facebook page, www.facebook.com/crs.parentconnection.

For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at rehab.alabama.gov/CRS and www.facebook.com/CRS.ParentConnection

'Eye' can speak with augmentative communication

by Emma Hereford, social work administrator

Have you ever heard the statement "it takes a village to raise a child"?

"The village" recently came to the Gadsden Children's Rehabilitation Service office to receive special training on a communication device for Zaileigh Jacobs.

Zaileigh is a client of Gadsden CRS who receives services through the orthopedic, seating/positioning/mobility and augmentative communication technology clinics. She currently uses an ECO2 eye-gaze communication device. The purpose of the training was to provide basic orientation for the device operations, establish a list of recommendations to meet short-term goals and objectives, and continue to evaluate Zaileigh's present communication skills with the device.

Sandy Baldwin, representative from Prentke Romich Company, was the trainer, and those being trained included Valerie Jacobs, Zaileigh's mother; Diane Hicks, Zaileigh's special education teacher at John Jones Elementary; Bethany Phillips, speech language pathologist and assistive technology specialist with Etowah County Schools; Ashley Morgan, speech language pathologist with Gadsden Regional Medical



Zaileigh Jacobs, a client of Gadsden CRS, receives training for her new eye-gaze augmentative communication device

Center/The Rehab Center; and Lora Chatmon, CRS speech language pathologist.

The participants reported that the training was beneficial. Zaileigh will move forward

with outpatient speech therapy over the summer and will be prepared to use her communication device when school starts in August.

LEWIS

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would be able to achieve in a brief period of time. Before this, I never imagined I would be performing tube feedings, dressing changes, blood glucose checks, nebulizer treatments, and administering medication. I also helped transport my grandmother to many medical appointments at the Cancer Center and other specialty providers and aided my family in navigating complex medical and insurance issues.

My career absolutely prepared me to be a better caregiver, social worker, and advocate for my grandmother until she passed away

in 2008, and caring for her gave me just a glimpse of the many responsibilities our CRS families experience on a daily basis.

While I was fortunate to have a large extended family who shared in my ailing grandmother's care, this familial support is the exception, and not the rule. Many of you work tirelessly with no break in caregiving, and receive little encouragement and no praise for the care of your loved ones. I have always held our CRS families in highest regard, and the experience with my family has made me admire, respect, and appreciate our wonderful families that much more.

My experience has also shaped me into a

better social worker. I constantly challenge myself and my staff to be better advocates for our families because I am so very passionate about our mission and believe in the work that we do. CRS plays a vital role in providing comprehensive and quality medical services to Alabama's children and youth with special health care needs and their families.

My new position and responsibility is one that I refuse to take lightly. Although I am saddened that I will no longer be providing direct services to our children and families, I am comforted by knowing my work will now have a broader impact on their services by affecting the policy development level.

Two girls' journeys beyond TBI

DEVIN'S STORY

by Desiree Hannah, parent

On Dec. 11, 2005, my two children, 2 and 4 years of age, were in a tragic car accident. The driver fell asleep at the wheel and hit a bridge going 60 miles per hour. My 4-year-old daughter, Devin, who was not properly restrained, was ejected and thrown 20 feet from the vehicle.

That night, I received an unknown call just as I was getting off of work. It was a police officer who called. He only said to rush to the hospital, and that my children were involved in a serious crash. He didn't elaborate, despite my pleading for more information, only reiterating to get to the hospital *quickly*.

When I arrived at the hospital, I was terrified of what I would find. I saw my son first. He was on top of a table crying while his leg was being X-rayed. I kissed his forehead and was relieved to see him alive. He was certainly beat up, but nothing like what I was about to find.

"Where is Devin?" I frantically thought out loud. The nurses could only point to a curtain which I first thought was a wall. Behind the curtain was my poor daughter. Devin was lying there unconscious, tethered to a manual respirator pump, which was breathing for her. Her head was bandaged and her body was covered in road rash. The doctors said she had bleeding on the brain and a fractured skull. Her injuries were severe, and they were preparing to airlift her to another hospital. They told me she might not survive. As terrified as I already was, hearing that was just too much to take.

They wouldn't let me fly with my daughter in the helicopter, and I was so frenzied and emotionally unstable that the hospital took my keys. Thankfully, I found someone to drive me to my daughter.

When I arrived in Huntsville, the hospital staff amazed me by informing me of everything they did for Devin. I decided to start a journal and write in it every day. It really helped me to express my emotions and track my daughter's progress.

The first day, my mother came up from

Florida to help with Devin. Together, we gave her a sponge bath. As we bathed her left leg, she moved it dramatically, and we were so happy to see this! I applied cream to her road rash, cared for her, and was holding it together pretty well. I still couldn't quite handle my emotions when the nurses came to change my daughter's suction tubing.

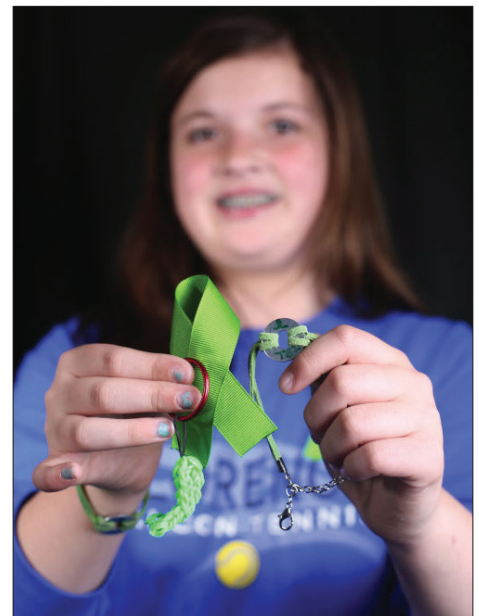
On the third day, the doctor told me they needed to change her breathing tube, as it was one size too big. A feeding tube also needed to be inserted through her nose into her intestines. The risk of removal of the breathing tube was potential swelling of the throat, remedied by a tracheostomy. The risk of leaving in the tube was potential surgery to repair damage to her throat. I chose to change it, and thankfully she was fine and didn't need a trach.

On the fourth day, they took her off the respirator, which was very scary. On her own, she breathed so slowly it seemed. She did great coming off it. The whole time we were in the PICU (pediatric intensive care unit) with her, we sang songs and read to her, all the while missing her sweet voice and the touch of her little hand. I placed her hand on my check and prayed for her recovery every day. On the fifth day, our prayers were answered. Devin opened her eyes! I can't describe the joy I felt in that moment! She didn't speak; she just stared around the room. But this was the beginning of her road to recovery.

From that moment forward, everything seemed to happen so much faster. She saw a speech therapist, who helped her re-learn how to eat. She began physical therapy (PT) to help range of motion and to strengthen her.

Devin was sent to Children's Hospital in Birmingham for more therapy, which was tough. PT exhausted her, and speech therapy upset her as she struggled to talk. We were put in contact with Suki Nelson, a CRS social worker, who assisted us with our many needs.

After three weeks at Children's, we finally went home. Still in a wheelchair, Devin communicated with a "thumbs-up" for yes and "thumbs-down" for no. With continued therapy, Devin started



Devin Kerby shows ribbons she makes for TBI awareness

slowly started walking again within a week of coming home.

Today, Devin is a 12-year-old survivor of traumatic brain injury (TBI) and an advocate! We still visit the doctor in Birmingham once a year, and we still have Suki Nielson as our social worker. Suki has been such an asset to us throughout the years. I couldn't ever thank her enough for all of the help and support she has given us. Devin still has weakness on the right side of her body, memory problems, and difficulty with fine motor skills. Despite this, she has done many great things in school, like participating in cheerleading, student council, and Girl Scouts, and serving as tennis manager. This March, she asked her school to participate in TBI Awareness Month. She raised money to donate to the Kevin Pearce Foundation to help others who have TBI. I was surprised and delighted that a young child would think to do something so honorable for others. Devin's school participated, wearing green for a week and taking up donations for the cause. Devin continues to raise money on her own, and the local TV station and newspaper ran stories on her efforts.

This little girl has overcome so much. Though she still struggles day to day with her disability, she chooses to make it overwhelmingly positive and plans to continue to raise awareness about TBI.

SAVANNAH'S STORY

by Melissa Watson, parent consultant

With the clock approaching midnight one July night four years ago, Jennifer's heart sank once she heard that sound.

With one knock on the door, she knew her daughter and granddaughter were in trouble. After all, it was late, and Mitzi and Savannah hadn't returned home that evening.

The deputies at the door told Jennifer that her loved ones had been in a horrible car wreck, and were being airlifted to Erlanger Medical Center in Chattanooga, Tenn. Her daughter, Mitzi, and granddaughter, Savannah, had been ejected from a vehicle that was travelling 85 miles per hour.

While her daughter's injuries were mainly to the pelvis and legs, Savannah's injuries were far worse. Her head immediately hit pavement, causing severe injury to her brain.

When Savannah's grandmother arrived at Erlanger, it was suggested she not immediately see Mitzi and Savannah for fear of going into shock. Doctors told her they would need to get through the first 72 hours before knowing more about Savannah and her prospect of recovery. In short, Savannah was not expected to survive this traumatic event, and doctors were not providing much hope.

Jennifer didn't leave Savannah's side and

stayed at Erlanger for four weeks to learn to care for her. Jennifer remembers distinctly the sounds of the respirator giving Savannah her only breaths. Rhythmic sounds of the monitors notching heartbeat, blood pressure, and oxygen intake are forever etched into her memory of those fateful days.

Savannah received a tracheostomy in her little neck to provide an airway and also to remove secretions from her lungs. She also had an intracranial pressure monitor placed through a small hole in her skull, secured by a bolt. This device allowed the NSICU team to intervene quickly if the pressure in her brain became too high.

Savannah was transferred to Children's Healthcare of Atlanta at Scottish Rite on Aug. 24, 2010, for day rehabilitation. They began rigorous therapy to help strengthen Savannah in all of her daily activities. The therapist taking care of Savannah connected Jennifer to CRS Social Worker Suki Nielson, who coordinates care for TBI cases in the Huntsville office. She worked with day rehabilitation staff and assisted Jennifer with medical follow-up appointments with specialists. She also assisted with providing a hospital bed, wheelchair, and additional medical equipment when Savannah was allowed to return home. Because she knew Suki was there to assist, Jennifer was able

to focus more energy on Savannah's care. Savannah's tracheostomy tube was removed during her stay at Children's Healthcare of Atlanta. She was able to return home to Alabama on Sept. 25, 2010. Savannah came home with a g-feeding tube, wheelchair, and lots of prayers and support. Jennifer was very enthusiastic about Savannah's return home. She truly believed that being home, watching her brother play, and being around family played a huge role in Savannah's path to recovery.

Savannah immediately began monthly sessions of physical therapy and occupational therapy at CRS and UCP; she was also heavily involved in speech therapy at Highlands Hospital. When Savannah was ready to go back to school, Suki assisted with special education eligibility and school transition.

With all of Savannah's improvements, Jennifer still wanted so badly to see her granddaughter walk again. Jennifer relied on signs from God and prayed for what was best for Savannah. One week before Christmas 2010, Savannah took her first steps since that dreadful July night.

Today, Savannah is in the third grade. She continues to have weakness on her right side, and also has both memory and articulation difficulties. She continues physical, occupational, and speech therapies at her school.

Savannah's grandmother says she absolutely loves school and is a social butterfly. Savannah and her brother, John, are in the same class, and they watch out for each other. Savannah loves singing, dancing and cheerleading and even told her grandmother that she wants to be a singer when she grows up.

While Jennifer has many goals for Savannah, most of all, she wants to see her granddaughter happy and to succeed in whatever her heart desires. She knows Savannah will do great things because she has already seen what great things God has done for her. Savannah is a miracle, and she is a heroine to her family and anyone who has the opportunity to meet her.

Said Savannah's grandmother, "We may not always understand why Savannah has had to go through so much, but I know with certainty that God has a mighty plan for this child's life."



Savannah Cochran thoroughly enjoys school, where she is known to be a 'social butterfly'

Family Voices launches campaign to highlight CSHCN

by Lynda Honberg

Director of strategic partnerships

Twenty-two years ago, my daughter Sarah was born with a rare genetic condition, and my life was forever changed.

At first, like so many other families, I was lost learning a new language and, despite my background in health insurance, navigating our managed care plan. Years later, I was fortunate to work for the federal Maternal and Child Health Bureau and relied on my experiences as a parent to fund grants to improve the system of services for children and youth with special health care needs.

But inside, I always wanted to be an advocate, which has led me to my current position as director of strategic partnerships for Family Voices.

Family Voices is a national nonprofit organization that works to keep families at the center of children's health care. Founded in 1992, Family Voices has a network of incredible family leaders in State Affiliate Organizations and Family-to-Family Health Information Centers who, like me, use their experience to be the voice for families and youth.

Our state family leaders provide information, assistance, and support to families of children and youth with special health care needs or disabilities across a wide spectrum of diagnoses and health conditions. Youth leadership is encouraged through Kids As Self Advocates, a national youth self-advocacy project. We also monitor federal and state legislation and provide information to help families and family leaders understand and influence the legislative process and advocate at the state and national level for policies that support



Director of Strategic Partnerships Lynda Honberg with her daughter, Sarah, at her graduation

the complex needs and situations of families.

I am thrilled to be a part of Family Voices as we embark on our new campaign – One in Five – to raise awareness that one in five families with children have at least one child with special health care needs. A few weeks ago, we held our Power Of Partnerships Family Leadership Meeting in Washington, D.C. Wearing our One in Five buttons, we went to Capitol Hill to educate legislators about the impact of having a child with special health needs. Many were not fully aware of the stress families experience trying to meet the needs of their child in a maze of multiple and complex systems of care.

Family Voices also has strong partnerships with multiple professional groups and is working on a number of projects to promote

quality family-centered care for children and youth with special needs. A few examples of our recent projects are as follows:

- The National Center for Family/Professional Partnerships increases the capacity of families, Title V and other providers to partner around full implementation of the Affordable Care Act (ACA); strengthens the primary care workforce through family/professional learning opportunities; and improves access to quality care and innovation in the areas of family-centered care, cultural and linguistic competence, and shared decision-making.

- IMPACT (Improving Maternal and Child Health Policies so All Children with Thrive)

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For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, susan.colburn@rehab.alabama.gov or Jerry Oveson, 251-438-1609, oveson@bellsouth.net.

Book Review

Epilepsy in Our Lives: Women Living with Epilepsy

by Kaarkuzhali Babu Krishnamurthy and Deborah T. Combs-Cantrell and edited Steven C. Schachter

by Odessa Taylor, CRS parent consultant

Epilepsy is a disorder that takes more planning than merely taking a pill once a day and an occasional trip to a physician.

This disability affects all aspects of life, including work, education, and family.

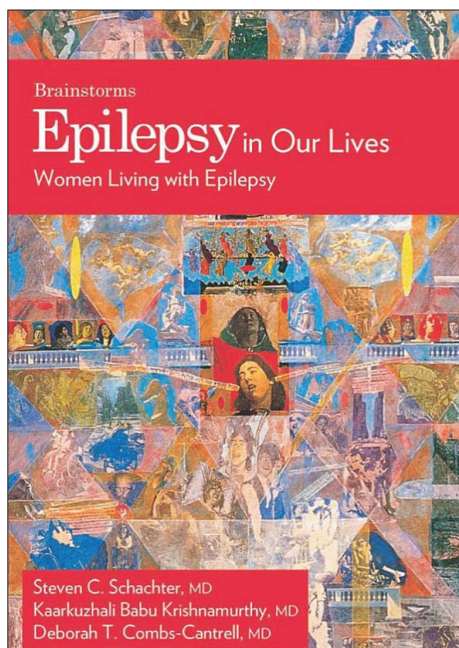
This helpful book contains several very

This book and others like it are available for loan in the parent resource centers at CRS offices around the state.

personal stories detailing how several women at various ages chose to cope with epilepsy.

The book is written in an easily accessible style that allows the reader to gain insight by peering into the daily lives of women who have epilepsy.

The collection of stories is written in the women's own words, with them detailing their struggles with the disorder and how it impacts them as mothers, wives, and individuals, and allows these women to



express their own fears and concerns candidly.

The compiled vignettes sample a variety of emotions and experiences associated

with the disorder, and the end result is an uplifting book that provides support for anyone who feels like the rest of the world does not understand her.

While few phrases have the potential to change your life like “your loved one has epilepsy,” after the initial shock, you will find that the condition will lead you down a wonderful path. This book states that epilepsy isn’t an end, but a new beginning.

Epilepsy can be contained, but it will never be “cured.” Healing is a process, and one which is never fully completed. This book helped me understand this fact, and if you face uncertainties with epilepsy, this book comes highly recommended because it details that everything happens for a reason. Sometimes those things are good, and other times they are not-so-good, but good things always seem to come from things that appear to be bad. Oftentimes, you discover that you have what it takes to cope with your condition and overcome your fears.

FAMILY VOICES

Continued from Page 8

focuses on health and wellness promotion for all children and youth, and offers information on a wide range of prevention topics. The project team worked with the American Academy of Pediatrics to develop English and Spanish versions of the Bright Futures Family Handbook.

- Engaging Native American and Spanish Speaking Families and Sharing Wisdom to Reduce Childhood Obesity is funded by the Patient Centered Outcomes Research Institute (PCORI). The project focuses on developing partnerships in Idaho and Washington states to empower Spanish speaking and Native American families and build a community interested in promoting

research on childhood obesity. We will apply for multiple-year funding with the intent to spread the initiative to other states across the country.

- Care Coordination Facilitation for Children and Youth with Special Health Care Needs in New Mexico is a partnership between the State Affiliate Organization in New Mexico, Parents Reaching Out, Blue Cross/Blue Shield of New Mexico, and Family Voices. It has provided information to families from Native American communities across New Mexico to help them better understand and avail themselves of their care coordination options under the Affordable Care Act (ACA).

- The Family-Centered Care Assessment is a quality measurement tool that measures new content areas in decision-making interactions, family support, community services, and cultural competence. Family Voices is partnering with the AAP to test the tool in pediatric practices.

Every day, Family Voices is making a difference in the lives of families of children with special health care needs. If you want more information on how you can be part of our growing organization and have an impact on One in Five families, go to www.familyvoices.org or visit our state affiliate, Family Voices of Alabama at www.familyvoicesal.org.

AN ENCHANTED EVENING

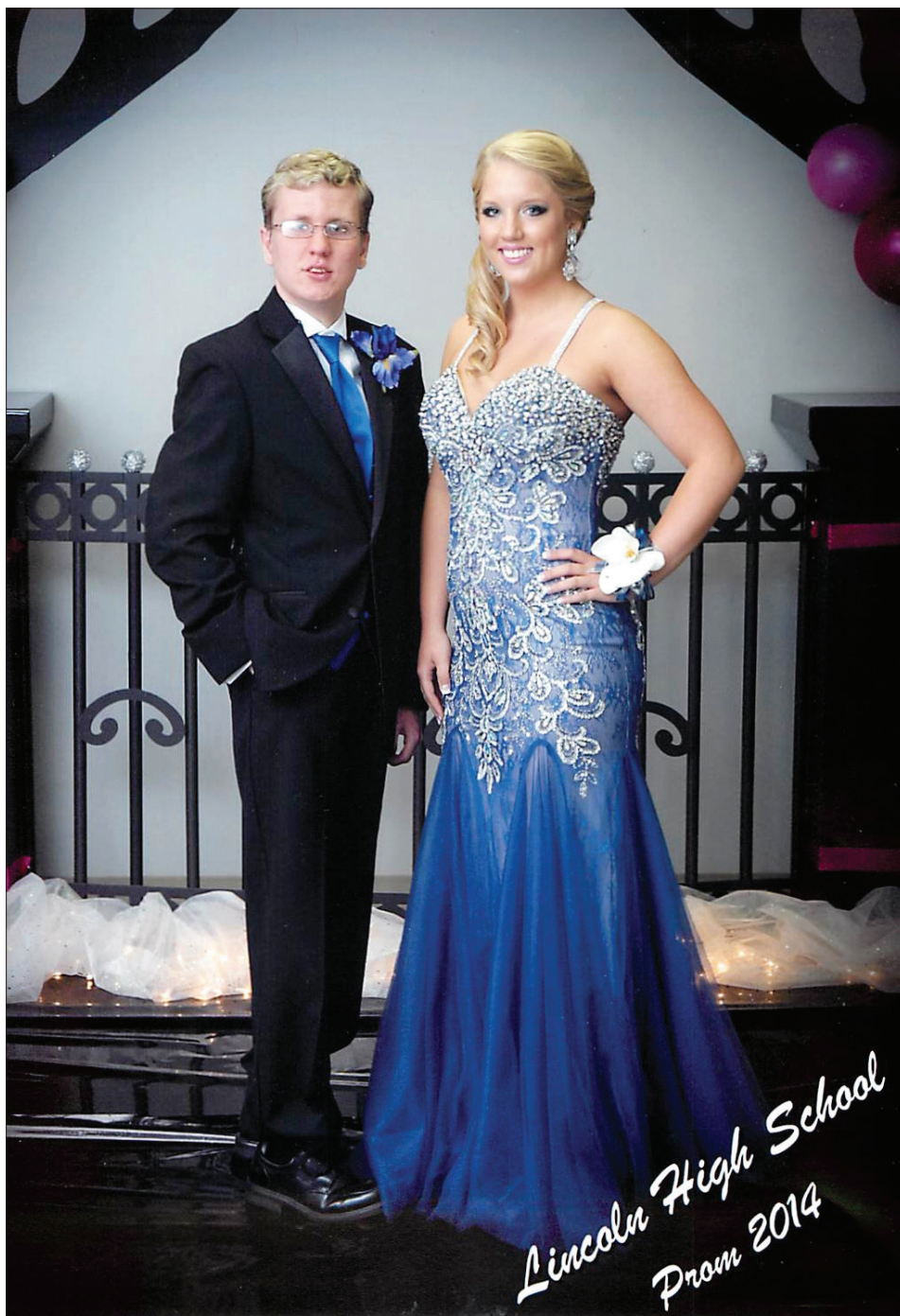
Dakota Butler, 18, was born with FGC syndrome. He has hearing loss and cognitive delay and wears leg braces. Having been enrolled in CRS since he was 2 years old, Dakota's progress has closely been monitored through many orthopedic and hearing clinics.

Even though he has had a difficult time with school, this 10th grader has always maintained a positive attitude through it all. An inspiration to those around him, little did he know that one amazing night at the Lincoln High School prom would forever change the attitude of someone else's life for the better.

Amanda Feenker, Dakota's best friend and date to the prom, said they first got to know each other in P.E. class last year. While walking the track together, they talked and got to know one another. She admired his optimism most of all. They became great friends because of his outlook on life.

Wanting a memorable, positive experience, Amanda decided there was only one person to ask to prom: Dakota. Of course, his face lit up with joy, and his excitement made her even more eager to go.

The two had a blast dressing in evening wear to go dancing, and in the process, Dakota changed her view in life for the better. Brimming with excitement, Dakota couldn't wait to share his prom picture with everyone, including his CRS family.



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Children's Rehabilitation Service

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Check Out What's Ahead ...

SILENT DINNERS

Description: The Silent Dinner is a signing-only experience, where you do not use your voice to communicate during the event. A wonderful way to get to know members of the Deaf community, local interpreters, and other persons interested in sign language in the Birmingham area. All dinners begin at 6:30 p.m.:

Sept. 11 - Johnny Ray's, 3431 Colonnade Parkway, Birmingham, (205) 968-8005

Oct. 9 - Habanero's, 1477 Gadsden Highway, Trussville, (205) 655-7380

Nov. 13 - Outback Steakhouse, 1944 Hoover Court, Hoover, (205) 979-7585

Dec. 11 - Red Lobster, 1030 Montgomery Highway, Vestavia, (205) 822-7240

Information: Wendy Lozynsky, lozynsky.wendy@aidb.state.al.us

Sept. 13, 2014

Special Education Advocate Academy

Description: A parents-only training event for families of children with disabilities from birth to 21. The academy will provide information to help parents understand educational law, policy, and practice to ensure better educational outcomes for their school-age children. Topics covered to include IDEA, the Alabama Code, advocacy skills. Event held at the Alabama Parent Education Center in Wetumpka. Deadline to register is Sept. 10.

Information: Contact the Alabama Parent Education Center, (334) 567-3352

Sept. 27, 2014

Child Safety Fair

Description: September is National Baby Safety Month, and to honor this, the Exchange Club Child Abuse Prevention Center will be hosting an event to raise awareness of child safety issues and decrease instances of child abuse and neglect. Event is from 10 a.m.-2 p.m. at the Jerry D. Coleman Community Center in Fairfield.

Information: Ruby Felton, (205) 801-5151 or ruby_felton@bellsouth.net

Oct. 4, 2014

Spina Bifida Association Montgomery Walk-n-Roll

Description: The Walk-n-Roll at the Montgomery Zoo is a family-friendly walk event to raise awareness of spina bifida and celebrate the accomplishments of the more than 166,000

Americans living with it. Registration is at 9 am.

Information: visit 2014wnrsbaofal.kintera.org, or contact Angie Pate, (256) 617-1414 or Jennifer Gray, (205) 417-5330

Oct. 25, 2014

Gadsden Bowl-a-Thon for Spina Bifida

Description: Join us at Paradise Bowling Lanes in Gadsden for a bowling event to raise money and awareness for spina bifida. Registration begins at 12:30 p.m., and bowling begins at 1.

Information: visit 2014gadsdenbowlathon.kintera.org, or contact Angie Pate, (256) 617-1414 or Jennifer Gray, (205) 417-5330

Oct. 29 - 31, 2014

2014 disABILITIES Conference

Description: The theme for this year's event is "Choices Shouldn't Be Scary." The conference, which is being held at the Perdido Beach Resort in Orange Beach, will feature a variety of sessions for self-advocates, family members, professionals, and direct support staff.

Information: Terry Pezent, tpezent@thearcofAlabama.com or (334) 262-7688

Nov. 7-9, 2014

Full Life Ahead Retreat

Description: A family workshop and retreat especially for families with campers in middle school or older. The retreat will focus on transition issues. A children's program is also available for siblings only.

Information: visit www.fulllifeahead.org or call (205) 439-6534 or (866) 700-2026 (toll free)

Nov. 17-19, 2014

30th Annual Early Intervention and Preschool Conference

Description: This year's conference, "Sailing with Flying Colors," celebrates children and families while providing information and techniques to families and professionals who work and care for young children with special needs. This conference is a venue that allows professionals and families to share in the learning process, organize and facilitate

legislative outreach, network, and often, find friends for life.

Information: visit www.ucpalabama.org or contact Jeri Jackson, (205)-823-9226 or jbh50@aol.com



Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.



CRS Parent Connection

Children's Rehabilitation Service
Alabama Department of Rehabilitation Services
602 S. Lawrence St.
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BACK-TO-SCHOOL WORD SEARCH

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U C S Y V E G G F G D C O S A
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